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ABSTRACT

The experiences and thoughts of numerous parents who have raised severely handicapped children are shared in this pamphlet. The pamphlet describes the life changes brought about by the birth of a severely handicapped child; stages in the grief process; coping strategies; the impact on siblings; the reaction of family members and the importance of family support; the changes in adult friendships; suggestions for forming partnerships with medical personnel; procedures involved in testing and evaluation and in determining the appropriate intervention program for the child; the role of the parent as a teacher; recordkeeping; and sources of information, support, and equipment in Louisiana and nationally. (JDD)

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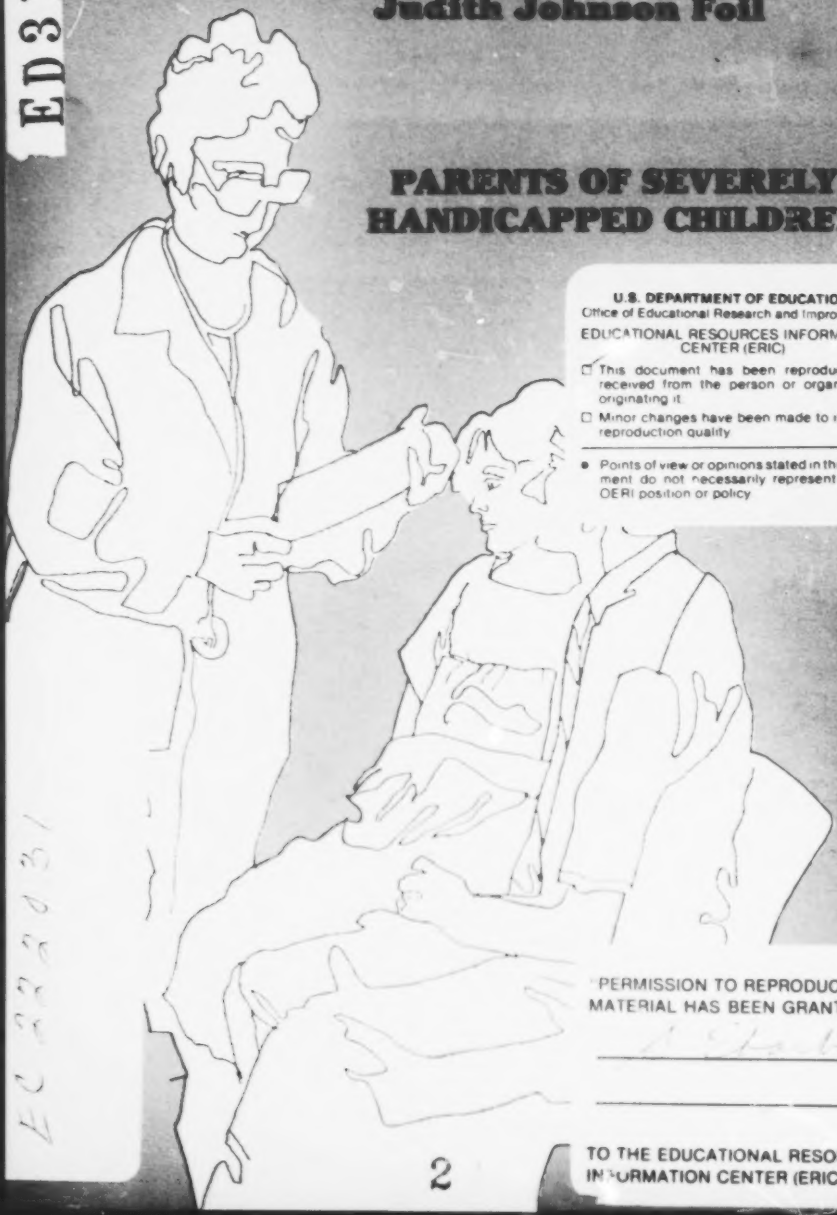
COPING AND CHANGING

by

Judith Johnson Foil

PARENTS OF SEVERELY HANDICAPPED CHILDREN



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PARENTS OF SEVERELY
HANDICAPPED CHILDREN

"Coping and Changing:

Parents of Severely Handicapped Children"

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Introduction

On August 12, 1977, Lauren Kathleen Foil was born to us, and from that time on, our lives have been changed in a significant way. Because her handicaps are many, some major, some minor, we often remember her first years as a blur, which came into focus only when we learned to manage her medical conditions. Once we mastered those, and she felt better, she began to smile, and very slowly she learned to feed herself, and finally to walk. Eventually, she learned to say, "No!," to read "Go," and even to jump. While she learned, we learned. We also drove, made phone calls, wrote letters, and had conferences. Now, we are able to be her advocates with doctors, with school personnel, and with society as a whole. Our goal has not changed. It has always been to give her a life more abundant, rich in experiences and opportunities. Meeting that goal has not been easy. Yet, whenever I am weary from the idea of sitting through one more speech lesson, making one more phone call, or one more doctor's visit, I think of the compassionate people waiting there for us, and I keep going. They are at therapy, at school, and at the other end of the telephone line, at their medical offices, and in their homes. They care too, and they make all the difference.

From the Author

In preparation for writing this booklet, I interviewed many professionals who work with handicapped children. I also had lengthy interviews with other parents. These parents shared their experiences with me in the hope that their sharing could somehow make your lives easier. Their children range from five months in age to seventeen years, and their handicaps cover the gamut. The children are mentally handicapped, brain damaged, deaf/blind, autistic, severely motorically impaired, and emotionally disturbed. Many have more than one handicap. These parents are at different stages with their children, yet they share common feelings. In addition, each one I talked to gave me new insights and understanding, and I hope I can pass these on to you.

I am grateful for interviews from educators at the State Department of Education, in its agencies, and in special schools; social workers in private practice, with various organizations, and with state schools; and several Baton Rouge pediatricians.

The contribution of the following mothers and their children made this book possible. In the text of the book, names have been changed in order to protect their privacy. Thanks to:

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Donna and Victor
Evelyn and Lisa
Mary and Brad
Gloria and Robin
Cindy and Jennifer
Dora and Shalon
Kathy and Glenn
Kerri and Danny
Sharon and Ashley Marie

How Do I Keep Going?

The following experiences are the compilations of the thoughts that numerous parents have shared with me.

I get my feelings out. I scream; I cry; I tell a friend.

I pray to God. I talk to my kids, my family, and people who care. They all keep me going.

I have a strong will. I'm determined to finish, and I'm a fighter. I try to stay optimistic, and I see every sign of progress as hope for the future.

I escape. I call a friend, someone to laugh with. I get involved with my other kids and their activities, with my nieces and nephews. I get a sitter and go out. I listen to music with my headphones on. I even imagine myself in a bathoil commercial.

I start with hope each day.

Changes

Joy, sorrow, excitement, depression - parents of handicapped children spend their days on an emotional rollercoaster of ups and downs; the peaks and valleys are never steeper than during the first years of their children's lives. For some parents, there has been the distinct possibility the child would not live. For them, survival alone brings joy. But, their child will be handicapped. Depression. A possibility the handicap will not be severe. Hope. The next day, an hour-long seizure. Despair. And so it goes in the lives of the handicapped and their parents. For days, for months, and for some, years, the cycles continue. At times, parents are lulled into a period of peace, only to be rudely interrupted by a medical emergency or the discovery of a new

problem. Although the years to come will bring their challenges, there will never be a more difficult time than the early years.

All of the parents I interviewed for this book are managing, but they have all ridden the rollercoaster. They have all ascended the mountain and plummeted down it many times. Their valleys have eventually become further apart, and they have become acclimated to their rare environment.

For all parents, the beginning is the same. They are devastated; they are shocked. The situation seems unreal. They stand outside themselves watching someone else go through this. Most of all, there is immense sadness. *"It was as if someone had given me a birthday cake and then taken it away."*

To relieve the pressure of the myriad of emotions the parents go through at this time, they talk. They talk to family, to friends, to medical personnel, and to clergy. They also talk with other parents of handicapped children and often find a new source of comfort there. Certainly, wives and husbands also turn to each other. They talk together and they cry together, but they cannot always comfort each other because they each feel such grief.

For most of the mothers, talk comes easily, but it is not that way for the fathers. Many begin to stay at work more than ever, and they frequently tell no one at the job. It takes them much more time to be able to talk, even to their wives.

Even for mothers, talking does not always come easily. Having to constantly explain to friends, acquaintances, and strangers is difficult, but having to tell their other children, and the grandparents may be the most difficult part of all. At the time when the parents need comforting most, they must instead reassure all these other people that life will go on.

While the parents do keep things going from day to day, they also go through a grief cycle. The child they believed would be born to them is gone, their "perfect" child is no more, and there is grief. Some people skip certain stages entirely, while others get caught in a particular stage for an extended period, but on one point they agree - the grief process cannot be hurried. Each person must proceed at his own pace.

After the initial shock, the next stage of grief is often anger. The people at the church nursery who will not keep a handicapped child but who will pray for her, the parents of the normal child who complain about his normal colic, the doctors who are unable to make the child well are all targets of our rage. There has to be someone to blame, and how can anyone blame the innocent children who cause all this chaos?

The parent may also experience a feeling of fear, a fear of being inadequate to handle shunts or trach tubes or whatever else may follow. *"I felt I had to be 'Supermom,' in gear twenty-four hours a day. If I let down, I felt guilt because I wasn't doing something."*

It is only natural then that, for many, a "frantic period" follows. During this period, the parents seek out every piece of literature available on the topic; they call anyone who might have information on treatment or services - from doctors to legislators. Indeed, they may go so far as to take special courses at developmental centers or colleges.

This frantic need to learn and to take action in order to make things better may also result from the feeling that the parent is somehow to blame for the handicap. Friends and family may wonder aloud what the parents did "wrong;" husbands and wives may blame each other and themselves. They may worry that they are being "punished" for not really wanting a child, for "suspicious" ancestors, or any number of other reasons. It may take a clergyman to assure the parents that a loving God would not single them out for this responsibility and that things do go awry in this chaotic world. It may be a doctor or social worker who is able to explain that, even with a reason for the handicap and an exact diagnosis, the problem that must be dealt with is the same. Life moves forward and today must be a beginning.

Another stage of the grief process is denial, and there is good reason for many parents *to* deny because the diagnosis for their children is often so elusive. *"Before the words cerebral palsy were actually spoken, I knew things were not right, but the positive outlook of friends made it easy not to face up to it." "I didn't admit that Ken was retarded until he was fifteen months though my doctor had told me at eight months. I simply did not 'hear' him, and I'd never have believed it if it hadn't been written on his chart."*

Fathers frequently seem to remain in the denial stage of grief longer than the mothers. *"The experiences parents go through are so different. In most cases, the mother dresses and feeds the child, gets the child into the car, drives him to the doctor or to the therapist, waits, gets a diagnosis or progress report, and returns home. At the end of a workday, which often leaves no time to think of home, the husband comes home and asks, 'How was the day?' "*

Nevertheless, it is hard to deny the existence of a severe handicap for long. In fact, the parents may be almost relieved to have their instincts confirmed, their questions answered. They take a step toward acceptance, but they still may have hope that their child will somehow miraculously escape the really devastating effects of the handicap, that he will be only mildly impaired. In truth, the very best doctors, thera-

pists, and teachers can only predict what this child will do. No one does actually know for certain. Because of this, parents may still aim high, while gathering the strength they need to care for their child.

After the parents pass through these stages, certain events will trigger their recurrence, but these events will usually be of shorter duration and less intensity. The most common setbacks come as a result of medical problems. A visit to the pediatric neurologist or a discovery of a previously undiagnosed problem, or even a seemingly minor illness, is emotionally trying. If the medical conditions cause feeding problems or constant crying, the parent becomes exhausted simply from feeding and nurturing. These demands take their toll, especially when added to constant planning for and coordinating of therapy sessions, doctor visits, and educational programs.

Another major problem seems to be adjusting to changes. Any change is hard, whether a move to a new city with its subsequent search for a new support team, or just a move from a caring and trusted teacher for whom the child will work. Seeing the other children during a first visit to an early intervention program often strikes parents with the realization of the difficulties to come. Parents seek similarities and differences between their child and those in the program.

Equally troublesome is the comparison of the handicapped child to normal children. *"It's hard to sit at family gatherings on holidays and see all the other children progress. I watch them play with Legos and build with blocks while my child can only sit or lie with a toy in her hands."*

All of these experiences are painful, but through sheer determination and persistence, some of the distress can be alleviated.

Coping

What courage, what bravery! Friends offer support with such words. Well, what choice do you have? You can stand up to this awesome task and try to follow it through, or you can crumble. That's it. There's no going back. You must be tough and gentle; you must be insistent and patient; you must speak up and listen; and you must be persistent even though you are weary. You will accomplish more during your child's preschool years than many people achieve in a lifetime. You will meet an immense challenge daily.

The first step in meeting that challenge is to attempt to gain understanding about exactly what is going on. *"It was a relief to read about the stages of grief and find out that there were clearly defined steps I had gone through and that I had only one left to go."* Parents are also able to get an idea of what their child will be able to do and what resources are available. It is time now to seek out the medical experts and learn how to tone down hypertonic muscles, to learn how to get the child with cleft palate to swallow smoothly. If the child doesn't sleep, it's time to increase his daily activities or to consider medication to help him. The satisfaction that results from solving these problems goes far to help overcome the paralyzing helplessness the parent originally feels.

Once some energy returns, the parent is able to take further action to reorganize and prioritize her life. For many parents, the house is the first to go. Sue said, *"When I was a clean nut, I was gripey all the time. Now I keep the floors, baths, and kitchen clean, but if the beds don't get made, I can't worry about it."* Catalogs, telephone shopping, and convenience foods save much time. *"Life will not always be so hectic, and later will be time enough to worry about making the crawfish bisque we love. Right now I just don't have the time or the energy to worry about some of the things I used to think were important. At this time, the simplest way is the only way to handle my life."*

Certain strategies can help the family get organized.

1. Keep a large calendar to write everything down on. Make each person responsible for getting his activities on it.
2. Have errand days. Ask a friend to bring her list also, and spend a morning together driving around to find the odd sized lightbulb or the right knob for the kitchen cabinet.
3. Divide the chores, at home and away from home. Sit and decide who will get up at night, who will drive which carpool, and who will buy groceries and pick up prescriptions.
4. Enlist the children's help too. They can learn to tie shoes and pour milk. Let the handicapped child help by waiting his turn.

Once some reorganizing is done and some activities dropped, there should be a little time to relax. Time just to talk together is essential for parents. *"We enjoy sneaking out for an hour for breakfast or lunch. A whole evening out counts as a major treat."*

There should also be time for family recreation. A change of scenery can cheer up everyone. Try packing the family in the car, and driving around a bit. Stop for yogurt, or just keep driving. If you miss exercising, try aerobics with the baby. It will take some creativity for

both of you to get a workout, but it will be worth it. Another idea is to tape yourself if you read or sing to the baby. These tapes, played at bedtime, can bring pleasure and comfort.

With careful organizing, a parent may find a moment alone at home, but she will have to be ingenious to snatch it. Getting up before the rest of the family offers a chance for the prayer and Bible reading that carries many mothers through the worst times. Each mother realizes, eventually, that she must have a few moments to herself, even to be able to scream or cry in private. It's difficult to remember that she has needs too, but the mother of a handicapped child must take care of herself if the child is to develop and grow.

Projects in the house and in the yard offer a temporary escape. *"At least with a yard project I felt a sense of accomplishment because it stayed done for a while. Once the azalea bush was pruned, it didn't need to be touched for a year!"*

Of course, the best relief at home comes from extra hands. *"When I was at the point of exhaustion, my mother and stepdad came and got up with the baby at night, allowing me the first rest I'd had since Kelly's birth. That was a turning point."* A time also comes when the parent must be able to get out of the house. This respite can come in many forms, and the need is great. *"My sister called and said, 'Get help and get out now.'"* *"Working saved my sanity. I had to be away a few hours a day."* *"Joining a health club was the best thing I did. Those few hours a week made a tremendous difference."* Work, a game of tennis, a weekend trip, or even a course in managing stress can all offer a reprieve.

There are two other "healers" that just happen without any action on the part of the parent. The first is that time passes. Even before the parents are able to function well, they cope by keeping this child alive and by getting themselves from one day to the next. This passage of time brings knowledge and understanding and allows them to regain some control over their lives.

Finally, for any parent, the best moments come when baby Lauren can finally push hard enough to make the red button on the busy box squeak. The tiniest bit of progress lifts parental hopes like nothing else.

Advice

The following ideas are a compilation of the suggestions for coping.

Don't dwell on the problem. Work on the solution. Accept your child's needs and go from there.

Find an adviser, someone who can help, someone to share your worst fears with. Find doctors who are compassionate, therapists you like. You can't do it by yourself.

It gets better and worse, but the sun will come up tomorrow. Take the days one at a time, and don't look too far ahead.

Put on boxing gloves and be prepared to fight. Be assertive and don't settle. Even if everyone says it's impossible, do your best to bring change.

Just love this child. She can bring you joy. Look at what she can do, not what she can't. She is a person first. Learn to love her as a person so the handicap doesn't matter.

Know that it's so much more exciting when this child does anything. See light in the little things.

Do what you want to do, not what you need to do. Take time for yourself. Be good to yourself.

You aren't alone. Get with other people and get involved. Build a network. It won't come to you.

Siblings

Chaos reigns. The baby needs her medicine, Matt needs help to tie his shoes, and Eddie wants someone to help him find the wheel for his dumptruck. One child rises each morning at five, one screams during the night, and all need attention all day. Each constantly competes for attention, and the parents try to meet every need, striving for family harmony.

The relationship of the siblings to their handicapped brother or sister is of major importance to the family. Reactions vary according to the ages of all the children, whether the handicapped child is older or younger, the functioning level of the handicapped child, and even the reactions of the parents. The siblings' immediate reactions usually mirror those of the parents in that they too are often excited to have a

baby in the family but terribly sad about the handicap. The major difference is that life goes back to normal much more quickly for the children than for their parents.

Just as the parents have mixed emotions about having a handicapped child, the siblings have negative and positive emotions also. Fortunately, in the long run, most siblings grow up with special qualities that a child in a family of "normal" siblings would never have the opportunity to acquire. Two of these qualities stand out. The first is that the siblings seem to grow up and take responsibility in the family more quickly than would otherwise be usual. Separations from parents, such as visits with grandmother, are accepted, and an air of independence at a younger than normal age is common. In the best of instances, these children are also able to forgive the moods of their parents, understanding the constant demands on their time. *"A doctor in Texas tried some experimental soy meal stuff. Well, the minute Mom heard about this she wrote and got it. We all want Lauren to have it as easy as she can."*

Another positive effect of having a handicapped child in the family is to make the siblings more sensitive to all people with handicaps, and especially toward their own family member. *"She can't walk or talk, but I love to play with her so I can make her smile. Everybody in our family helps her with her work for school like balancing her on her feet. I'm glad I've had this experience. The way I help her, I could take any kid you gave me. It's exciting watching her learn things."*

Outside the home too, they rise to their challenge and become protective of the handicapped child, defending him if necessary. They intercede for him and in some cases communicate or interpret for him. Kelly at five accepts Kim matter of factly. *"This is my sister Kim, and she doesn't talk."*

There may be negative reactions too. These can happen with any new baby, but are often exaggerated with a handicapped baby because of the enormous amount of attention he requires. The good news is that the positive reactions are the ones that remain.

As might be expected, young siblings may cry for attention, suffer temporary reversion, and display anger at the mother for delivering the "intruder." *"While I was recuperating from the birth of Jennifer, I had to force a hug from big sister Melissa because she was furious at me."*

This anger may cause the sibling to feel guilty, and the parents have to be attuned to that possibility. They must allow the normal child to verbalize those feelings. *"I made sure Jan always had a few minutes at bedtime so that she could release her anger at her brother for his*

verbal abuse of her. Although she knew he was emotionally disturbed, it was impossible for her not to be affected when he told her she was fat and stupid."

If the normal child is younger, there is usually less of an adjustment problem because he is born into a family with a handicapped child. In fact, Lynette remembers that everything her normal child did seemed brilliant, so she received frequent praise. Unfortunately, as the normal child grows and sees other sibling relationships, there may be disappointments. Matt was frustrated when Julie couldn't play with him; he missed her companionship. There is less play, as well as less fighting, when one of the children is severely handicapped.

Finally, brothers and sisters may possibly be embarrassed by their peers making fun of their sibling. Peggy remembers Troy's concern that his friends would make fun of Victor. As it turned out, the other children viewed him simply as "a baby" and reacted positively. In Debbie's case, her daughter was older and her classmates did stare. Debbie spoke with the teacher, who gave the class a brief lesson on being handicapped. A positive experience resulted.

Two areas are the most difficult for the parents when dealing with the brothers and sisters. As a result of being fatigued, tempers may flare, and the siblings can often be the targets of their parents' anger and frustration. Therefore, the parents must make a conscious effort not to overreact when meting out punishment. *"As a four-year-old, Josh should be allowed to spill milk too, but it's hard to remember that he is a child because he can do so much more than his brother."*

Because they seem so capable, it's very tempting to let the siblings become extra parents, to make them full partners in meeting the demands of caring for the handicapped child. It's so convenient to have them babysit, help feed, and help dress him. In the long run though, the more positive their feelings are about their sibling, the better for all concerned.

If the children are near the same age, they may play together with the parents participating in the activity. Patti remembers hearing herself telling Holly over and over, *"As soon as I finish with Matthew, we'll do that."* To counteract that problem, she and her husband designated Sunday afternoon as Holly's time. Although Matthew goes along, Holly chooses the activity, whether feeding ducks or visiting Mike the Tiger at LSU. Dora also plays with her children together. *"Both children like to tumble with me on the waterbed."* Troy does help in the care and teaching, but he also gets involved in the play.

Just as parents need time alone away from the handicapped child, so do the siblings. It's important for parents to encourage the nonhandi-

capped child to participate in extra activities. While that child is practicing soccer or ballet, she's getting attention from another adult.

At school parents can be helpful by letting the teacher know what is going on at home. In the classroom most teachers are willing to give a child a little extra attention until he adjusts to his situation. If the mother can work it out, it may be important for her to be roommother or to do something else special at school.

At home, parents need to find a quiet time for each child. They may stagger bedtimes, giving each child a visit then. If the handicapped child is in school or takes naps, that's another chance for one-to-one time.

Certainly relationships change, sometimes on a daily basis. For most families, the effects of the handicapped child are more positive than negative. *"Before, I focused on Jeff's faults, his messy room, his problems with grades. But his love for his sister and the responsibility he showed in dealing with her gave me the opportunity to see a side of him I might not have seen otherwise."*

Families

Of the parents I interviewed, exactly half felt that their families gave them terrific support. They gave that support in every form from driving and cooking to calling and listening. The other parents truly missed that support, but some of them who received no help at first, received it after the relative came to know the child and understand something of his handicap.

The parents whose family members "come through" benefit in two main ways. The first is respite care, which includes everything from a sister changing a diaper to a grandmother taking a year's sabbatical to help. The extra help makes a world of difference. *"That one weekend a month my parents kept the baby was about the only thing that kept me going. I knew that no matter how bad things got, I could look forward to two whole days without the responsibility of caring for my child."*

The other benefit is the moral support family members give by taking pride in these newest members of the clan. *"I saw my parents standing in front of the nursery window saying, 'That's ours!'* " In other instances, siblings may offer support with words of comfort. *"My sister said, 'It is just fine to feel that life's not fair. It's not. You feel anger. You feel hurt. Don't apologize for that.'* "

In sharp contrast to these grandparents, aunts, and uncles who accept the situation immediately, are other family members who simply deny that anything is wrong. They aren't ready to hear, say these children are "just lazy," that they'll get better, and surely things will all work out. *"They loved Jeffrey dearly, but my dad just couldn't say the word 'retarded,' and my mom prayed constantly for a miracle."* Others who deny may just stay away, never confronting reality.

Some turn away because they are afraid and feel inadequate to handle the child. They fear they don't have the stamina or the skills to handle a seizure, or that they will hold him "wrong." Others do not feel comfortable with discipline, or they constantly feel pity. It is impossible for them to treat him like other family members.

With patience and tolerance on all sides, relationships usually improve. Several suggestions might help.

1. Tell your family you want them to spend time with your child and get to know him. Help it happen.
2. Tell them you want them to learn about his condition and how to take care of him. *"My family learned to tubefeed my child right along with me."*
3. Help teach them. *"I taught my whole family to sign to Brad, so he could participate fully in family gatherings."*
4. Let them know if you need or will accept financial help.
5. Most of all, let them know when you're tired. If they don't offer, ask them to babysit or to help with household chores. *"I was tempted to say to my prayerful mother-in-law, 'After you've finished praying, could you come help me cook?' "*

The parent of a handicapped child learns early that, even with family members, he must be an advocate for his child, speaking up and sharing his feelings.

Friends

A friend is a person who cares for us even if we're too tired to make conversation or too down to make jokes. Unlike our family members, we choose our friends and they choose us, and those relationships change constantly throughout our lives as we add new friends and occasionally lose contact with old ones. The birth of a handicapped child offers us an opportunity to form new relationships and to grow closer in old ones.

Just as all other relationships change when a child is added to a family, so do the relationships with old friends. Most of them readily accept the handicapped child. *"It never occurred to me that anyone*

would turn away from my child. If I'd had a purple child, I'd have expected any real friend to say, 'She's a lovely shade of purple.'"

Regrettably, friends also have to deal with their own sadness and bewilderment at what has happened. Because of that, they aren't always able to be the source of comfort the parents expect. *"Though I expected the most from my best friend, she couldn't give it. She was too devastated herself."*

Parents are torn between wanting to express their feelings of sadness and resentment, yet dreading their friends will not be able to handle the situation, not want to face it, and, therefore, cut off contact. *"My friends called a mutual friend to ask about me. I guess they were afraid of what they'd hear if they called me. Maybe they were afraid I'd cry."*

It's so difficult for them to understand that the crises are continuous. The best of friends get tired eventually. *"I lost them all. There were those who came for the first surgery, but they didn't make it to the twelfth."*

Most of all there is just very little time to keep up with friends. *"If I ever had time to initiate a call, I didn't have the energy."* The changes in lifestyle force a change in patterns of friendship. *"I'd want to have friends over, but by the time they'd arrive, I'd be so tired from the extra effort, I'd be almost angry at them. As the evening progressed, I'd relax and enjoy the conversation, but I might wait a long time before I'd do it again."*

It is still harder to take this child out with friends because of the unpredictability of what might happen. *"As soon as we got to the picnic, Jennifer had a seizure, and everyone was running around and frantic." "We'd decided to celebrate and go out for supper. I watched, appalled, at the restaurant as Eric turned over a table that had just had $45 worth of catfish placed upon it."*

Parents also get tired of constantly explaining to friends. "No, he really is no better, or yes, we've had another crisis." One parent finally decided to answer queries with a long Christmas letter to bring friends up-to-date.

Although friends don't really quite know what to do or say, they do care. *"Our friends offered strong support emotionally and physically. Meals were delivered to us for weeks while I shuttled back and forth between home and the intensive care unit at the hospital."* Friends visit, keep other children, write, pray, listen, and care. *"I may have fewer close friends now than before, but those who did stay with me are jewels."*

Medical

"Parents who are advocates, enthusiastic, and never give up make it, and so do their children." This quote from a Baton Rouge pediatrician points up the strong role parents play even in dealing with the child's medical problems.

Because the problems of the handicapped are unique, and there are more frequent doctor visits, many more complicated and puzzling symptoms, and more difficult decisions to be made, it is of major

importance to the mother that she establish a rapport with the doctor. In extreme cases, his trust in her instincts and his willingness to act on her suggestions can make a major difference.

The number one criteria by which parents rate pediatricians is by their willingness to listen and to actually hear the parents when they talk. There *are* "good doctors" who listen to all the "silly questions" and consider the parents' "theories." If the mother occasionally takes the child in when it is not necessary, these doctors understand and treat her concern as important, although the illness may not be. Further, these doctors go slowly and return and initiate calls. There is always an attitude of caring about the child and his parents. These doctors look at the parents as people with special needs also. *"The specialist I went to see at Emory said, 'I'm going to put you in a private room. You really need the rest.'"*

Another quality the best doctors have is an interest in these particular children. They look at treating them as a challenge, they notice and praise the slightest progress, and they tell positive stories about patients with similar problems.

Unfortunately, you may find yourself with a doctor you would like to work with but who isn't handling things the way you prefer. If so, you'll need to help him. It's entirely possible you're more of an expert on your child's specific condition than he is.

For example Mary charted Brad's vision fluctuations for two years to make her point to the doctor, and Sharon found that the quickest way to get a change in medication was to chart her child's behavior. If feeding is a concern, you might save an office visit if you keep a log before the visit recording the quantities and times of feeding. Sometimes, the log is surprising even to the parent. Be sure your descriptions are accurate so the doctor can understand what you're saying. This efficient approach gives a parent credibility.

Once you are at the doctor's office, there are several things you can do. If between visits, you keep a running list of questions, just as you would a grocery list, then during the visit you can ask them all and write the answers on the list. With this method you can actually look at them again later instead of just trying to remember. While you're at the office, you and the doctor need to determine a specific course of action. If you feel you need extra time, consider scheduling a consultation session with him.

Precisely because these caring doctors are out there, the parent must not hesitate to hunt for one if her doctor is truly inadequate. A major complaint concerns the doctor with the patronizing attitude Ann remembers as, *"Me doctor, you dumb mother."* If your observations are

telling you your child is not being treated properly, consider asking for a second opinion.

Sometimes a doctor is so inflexible, so certain that his theories are right, that the burden of taking action is placed on you. The doctor is likely to blame all medical problems on the already identified handicap. A child with Down Syndrome may grow very slowly, but he will grow. No growth at all could be a sign of a hypothyroid condition. Whenever a child REGRESSES or STOPS PROGRESSING, the parent must seek help.

Unfortunately, these second opinions can be confusing. Doctors may differ among themselves as to a course of treatment. One orthopedist recommends full leg braces, another feels they won't work for this child, while a third feels they're obsolete in any case. You, your pediatrician, and these specialists must determine the course of action to pursue. A doctor for a special child must be willing to work with others - to consult - for the problems are too complex to handle alone.

Other doctors are faulted for being blunt and insensitive. Joan's doctor was "too busy" to wait until her husband could be with her to receive the diagnosis. Deborah remembers the doctor who told her she'd certainly be better off if her child didn't make it. If the doctor can't take the time to provide comfort, to answer questions, and to return calls, you should certainly consider changing.

Few parents blame their doctors for incompetent care, but that can occur. One pediatrician failed to recognize that the unusual lump on the child's head was the shunt, which had gotten out of place. An otherwise competent doctor may wait too long to act, causing a need for emergency procedures. If these things happen, the parent must get to another pediatrician fast with the least of her worries being the first doctor's hurt feelings. The child must always come first.

If you decide you must change doctors, this difficult decision may have to be made when you are emotionally drained and in no mood for a confrontation. However, there are ways to make the change easier. If you wish to tell him directly, a pediatrician suggests you say, *"I'm unhappy with the way things are going. Maybe I'm overly concerned, but I feel I need a change."* Another method is to sign a release of information form and get the new pediatrician's secretary to get the records. If you wish to talk to the first doctor's secretary, just ask for the records to be sent, but don't feel you must explain.

To help you choose another doctor, you may want to ask other parents at an Early Intervention Program, doctors you trust, social workers, or other professionals for referrals. Before you make a final decision, you'll want to ask him some questions.

1. How do you feel about, and do you treat other handicapped children?
2. What are the office hours?
3. Who takes your calls, and will that person trust my word if I call in an emergency?
4. What happens in an emergency? Do I get the emergency room doctor or you?
5. Do you allow patients to look at or make copies of their records?

A good doctor has many facets. He's knowledgeable but knows his limitations, he's available, and he's a good listener. *"He's not an in and out doctor. He takes time to play with my child, to work with her."*

Testing and Evaluation

"It's a nerve-wracking experience. Everyone knew what was going to happen but me. There I was with six experts who would determine to a large extent the next three years of my child's life. What were they going to do to me?" Though the evaluation team members do what they can to put the parents at ease, there is no way to minimize the importance of a major evaluation.

The first complete evaluation by the pupil appraisal team in a local school system or other agency occurs when the child is suspected of being handicapped. This can occur as soon as the baby is medically stable and out of the hospital, although it usually does not come until later. Subsequent evaluations occur at least every three years. These evaluations determine the child's eligibility for available special education. After the evaluation, an Individualized Education Program (IEP) is written for him to detail his program and placement if he will receive special education services.

An evaluation may be difficult because the parent is hearing from an authoritative voice that his one-year-old son is functioning at a three-month level. On subsequent evaluations, if progress has been slow, it's discouraging when the gap has widened. On the plus side, accomplishments the parent may not have thought of as significant may show the evaluators that the child has greater potential than expected. At successive evaluations, the parent may be surprised at the child's progress. *"Sandra's I.Q. went from twenty-four at her six year evaluation to fifty-two at her nine year one. Though they did use different tests, significant progress was undeniable."*

These meetings can intimidate the parents, but there are steps a parent can take before, during, and after the evaluation or the IEP to make them easier. Several weeks before the evaluation the parent should update the child's medical data. If both parents will not be able to go to the evaluation, a friend or relative might be drafted for company and support.

During the evaluation, the child may not "bat the red pompom," although the mother knows he can. Part of the problem may be that he won't perform for someone he doesn't know, or he may not perform in a testing situation. Retesting may have to be arranged. On the other hand, the evaluation may be accurate, but because it doesn't show personality, the numbers tend to be lower than expected. Although it may seem that it would be impossible for an evaluation team to assess

a severely handicapped baby, it is possible. Regrettably, it is also possible that the testing may not be appropriate. *"They showed my baby cards to check his eyesight. I couldn't even recognize what was on the cards. It really unnerved me."* One parent feels that sometimes evaluators may be unreasonable in asking for more testing, while another parent might want a test repeated to be sure the information is accurate. The parent has the right to speak up in either situation. Children do change, and evaluators will differ in their focus and interpretation.

The role of the parent remains the same. It is to be active and involved and to ask questions at the end of each testing period. If he disagrees with the evaluation, he needs to ask for a reevaluation or a partial reevaluation. The state provides for this case and can do this.

The other major assessment is the IEP. Before meeting to determine the IEP, the parent can assemble medical records and reread the information from the evaluation. She may also wish to check that information against articles describing normal development to determine the goals she wishes to include on the IEP. It is hard to choose between objectives such as sitting and talking, but she must decide what the child needs to learn most at that time. Next, it's a good idea to read the pamphlet on IEPs, and to ask for a list of program options and where they are located. Finally, the parent may wish to line up a friend or someone knowledgeable about the child to attend this meeting also.

One important feature of IEPs is that nothing can be written down on them ahead of time, but they must be planned before the meeting. THIS ASPECT IS SIGNIFICANT FOR THE PARENTS. The rationale behind this idea is that the team, including the parents, should put this together as a group obtaining one another's input. The reality is that each teacher prepares his goals, brings them to the meeting, and then writes them in the IEP. Indeed, no one would want an IEP dictating the child's program for twelve months that hadn't been considered ahead of time. The problem is that, while the rest of the team knows at least some of what will happen at the meeting, the parent knows nothing. Since there is no rule that would keep a parent from asking teachers and therapists ahead of time what they plan to recommend, a preconference with the teacher(s) might ease the parents' nervousness and make the actual meeting go more smoothly.

Once the IEP is completed, the parent must double check it carefully, not relying solely on the trust he has in this group of teachers. If a teacher or the child leaves that school, the IEP protects the child's rights to the services the parent feels are important. Therefore the parent must let the evaluators know if he feels an additional goal needs to be added to the IEP or if a reassessment is called for. At this point, the parent can refuse to sign the IEP, but he should be prepared

for pressure at the idea of having to reconvene the six, busy experts. In spite of this difficulty, it SHOULD be done if called for. The need for related services such as physical therapy or occupational therapy can be considered separately if the parent wants to accept the rest of the evaluation. For instance, when my child was deemed to no longer need occupational therapy, I disagreed. After a re-examination, she began to receive services again, but it took three months of phone calls, conferences, and my determination to get her retested for therapy. The rest of her I.E.P. remained unchanged.

Being an advocate for the services you want for your child becomes a way of life. Your voice will be heard, but it must be loud and persistent. You can make the difference.

Program

"Parents have power." Is this true? Well, no and yes. There are times when you face "the bureaucracy" that it seems as if you have no say at all. But "veteran parents" know that perseverance will pay off, and you do have power. The kind of educational program you would want is a legal right once your child reaches three. Although the school system may not provide what you want, federal and state laws are on your side. However, before the child is three, you must rely on your community organizations for most services, and the scope of these programs varies from area to area.

If you are lucky enough to have a well run program, the benefits are many. Parents learn to let go and children learn to separate from and to relate to different adults. At nine months, Marci was riding a bus and staying at school all day. *"I missed her, but I could not do for her what they could. It helped lots not to have to [illegible] with the problems all the time."* After Sam left for residential placement, Cynthia felt relief. *"We really had no choice. He'd become too aggressive and difficult for us to handle."*

As soon as you are ready to seek some sort of program for your child, you can check out the possibilities. An impressive number of resources exist in Region 2, but before the age of three, a comprehensive program is not available through any single agency. The ARC programs for children zero to three are the most frequently used. These early intervention programs offer homebased activities to all the children, and some offer centerbased instruction. Many offer a short-term transitional class for those about to enter a full-time program, and a few progressive programs are considering daycare components. If your child's specific condition is not addressed by the existing programs, you may have to use your "power" to get an appropriate one.

If you are fortunate enough to have a choice of programs, you might wish to ask some questions of the director of each.

1. What is your pupil/teacher ratio?
2. What are your discipline techniques?
3. How much time is spent on speech and motor skills?
4. May I observe the class whenever I wish?
5. How do you keep data? Do I get a copy?

You may also learn by observing the class and by talking to the teacher and to the parents of the children in the class.

If there is a possibility of residential placement, the rules are almost the same: read and determine what you want, find out what's available and visit, and evaluate the family situation. If a child's needs can only be met by a near twenty-four hour program, a residential placement can be best. If it doesn't work, a change can always be made. Community agencies are working to provide the support and respite to allow all severely involved children to stay at home, but it's not available yet.

When you decide to send your child to his first program, you may find it difficult to trust him to anyone else. *"I put him on the bus, and he laughed, but I cried."* If the child sheds daily tears, it is even tougher for the parent to feel she is doing the right thing. *"The first year at school she cried daily. She had never been in a nursery, but I knew I had a job to do. She had to have an education. I took nerve pills, but Shelly went to school."*

Once the initial adjustment is past, the parent may discern a need for change in the program. At that point she needs to get to know the teacher, volunteer in class if practical, and observe. She has a chance to learn. *"I watched through the glass and saw my child as others see him."*

After this "short course," if a need for change is confirmed, the parent must speak up. Cindy said, *"At the new program, the children lay around while the teachers cut out paperdolls. They didn't even bother to continue Susan's potty training as they had no potty. They were also scared of her stunt. It was a disaster. I called the director of the program and was able to get a potty for her and a book on stunts. Though I feared their reactions, the teachers responded well."*

At three, the child moves to the program provided by the local school system. Certain tactics can facilitate the entry into such a program.

1. Consider joining the parent group.
2. Get the old and new teachers together for an inservice session at least by telephone if they have time.
3. Let the child go part-time at first if that option is offered.
4. Praise the new school to the child and his performance there.

Occasionally, there may still be problems. *"We have come across a few instances of not knowing our rights, and we may not be getting as much as we should, for example, in speech. There needs to be more openness in things like determining how much time with the occupational therapist or physical therapist. We're not qualified, they're educated. But if the law says we can have it, we want it. Don't hide it from us."* In order to get the desired services, the parent must be firm and remember, these professionals have their jobs because of these chil-

dren. In certain situations, a parent may have to call and call again, wait on hold, and then call one more time.

Occasionally, drastic measures have to be taken. After numerous phone calls and meetings, Toni told of having to threaten a due process hearing to get an aide to handle her child's tracheotomy at school. She knew her rights, and once the administration realized she was determined, she did get the aide without the hearing.

Fortunately, things don't usually go that far because you can negotiate, give suggestions, and work with the program to get what you want. Usually, the teachers and administrators want what you want, what is best for your child. *"The entry of these new people into our lives was the best part of my daughter's being handicapped. Under their guidance, I saw her do things she'd never tried at home."* These people also offer a gift of understanding, which few other friends have. *"They encouraged me to share my burden. Janet, Molly, and Becky were there to share the responsibility with me."*

Parent as Teacher

The concept of parent as teacher is not unusual. A major role of any parent is to teach, but with a special child, there is much more to be taught and the teaching is more difficult and more time consuming. Activities of daily living that normal children do naturally must be taught to the handicapped child. In the beginning, even feeding and chewing can be a problem. Debbie found that Katy's feedings got much better when she got a college student to work along with her at each meal for a couple of weeks, using the techniques taught by the occupational therapist. Once a child can use a spoon, feeding can still take so long that one meal almost runs into the next. *"I let him feed himself his favorite meal (breakfast) and let him make a total mess once a day. I help him at the other ones."*

After feeding, the next goal is usually to work to get the child moving, rolling, and creeping. Many parents follow a regular schedule of exercising the child that may include an exercise/playtime after baths, stretching to videotapes with music, or even work on the parallel bars for a child with cerebral palsy. Weekend exercise sessions and plain old roughhousing - usually totally unstructured - may be enjoyed by the parent as much as the child.

In addition to the exercise, parents also find time daily to teach activities, such as how to pick up toys, sort silverware, or use light switches. They help him fit into his environment, and teach him awareness, eye-hand coordination, and problem solving skills. Sessions are more interesting for the parent and hold the child's attention longer if they alternate between activities the child enjoys and those he doesn't, constantly varying the routine.

The handicapped child must learn social skills, too, for they may well be more important to her than the cognitive skills. Because she will interact with people many times a day, she must learn to eat with good manners, say thank you, and allow other people to talk without interruption. As she gets older and goes out in public more frequently, appropriate conduct becomes even more important. *"I had to teach Chris not to hug strangers. She had to learn that hugs were for special people."*

The most difficult of the social skills to teach is good behavior. It's hard to chastise a child who is severely impaired. Disciplining this child goes against all the principles we've learned, and yet it is absolutely critical that it be done. Nobody likes a bad child, and with all the

care and attention from others that a handicapped child needs, he just can't afford to be undisciplined.

"Be the boss. Be firm. If he wins one battle, he expects to win more." All these words from veteran parents emphasize one idea: set rules you and the child can live with and follow through. *"I have only two rules, there is no deliberate spilling and no playing with food in the mouth. We can both live with those, but if they're broken we just try again."*

Behavior modification, a program to change a specific behavior, is the method of discipline most commonly used. It can be anything from several five minute sessions throughout the day to help him keep his fingers out of his mouth to a very structured activity for an autistic child. A child may lose her self control. For this child, "time out" in a "sad chair" can work well. A timer is set for ten minutes, and the child knows she can get up when the bell rings.

If you've been able to find a punishment that bothers your child, such as the "sad chair" or taking away a privilege, or a reward he'll work for, such as a hug or an encouraging word, it will be much easier to modify his behavior. However, finding the incentive can be a real challenge. The one thing the parent must never do, is to reward bad behavior by giving in to it. Disciplining a toddler is not easy, but dealing with an eight-year-old who still throws tantrums is much worse.

Another strategy is to try to prevent the chance for bad behavior. For instance, when taking the child out, keep it brief, and plan trips that can be cut short if need be. Choose the destination carefully (a small neighborhood store might work best.) Try to enlist the child's cooperation by making sure he understands what is expected of him. If there's a problem with getting him to walk with you, distract him by walking backwards or singing on the way to the car, or offer to let him carry a package or some keys.

If these ideas fail, go to "Plan B," which is to forget public opinion and ask for help if you need it. Briefly explain what the problem is, tell the person there is no danger, and say, "Will you work with me to carry this child?" The positive attitude of the parent can reassure the public and help the child to calm himself.

With all of these things to teach, many parents start with brave resolutions to do exactly what each specialist has suggested and do it several times a day. They soon find that they and the child have a hard time keeping it up.

At that point several things may happen. The parents may continue at full capacity but find that the handicapped child is their whole life,

or the parents may quit doing so much, but feel guilty whenever they aren't working with the child. Everything they read will seem to be screaming, "Each opportunity not seized is lost."

In the best case scenario, the parent realizes that she can handle things best without a strict schedule. She can work in a little exercise while waiting for the pediatrician, a little talk while changing the diapers. The best results will come from pulling the child into an everyday environment and focusing on what he's interested in. If possible, parents, siblings and grandparents can all take turns in the role of teacher. Constantly varying the routine, using as many activities as possible with built-in reinforcement, such as turning on a faucet or a radio, holds the child's interest longer. Putting a few toys away for a while can make them much more interesting when they reappear.

The parents often feel they teach constantly. *"This child needs everything I can give, and I do get tired, but when she takes even a tiny step toward a goal, I am rewarded by a wonderful feeling of achievement that serves as a balance for all those other days when all my repetition achieves no results."* It often seems it would be much simpler just to do all the feeding and all the carrying. Independence seems impossibly far down the road, but the parent of a handicapped child cannot take the easy way any more than the child can. Deborah urges, *"If the child is capable, don't make things easier. You should push him to work at his functional age level, not his chronological level, but push him you must."*

"Handicapped children are not born to special people, but through caring for their children, these parents become special people."

Sources of Information

There are many sources of information about handicapped children, and they cover a wide variety of topics. A comprehensive list would be much too long to include, so a sampling is listed below.

State Department of Education - booklets or information are available on:

- communications for the severely handicapped child
- the schools for the deaf and the visually impaired
- the grief process
- the child's legal rights to education
- how to file a formal complaint
- the developmental stages (Minimum Standards for Severely Handicapped Students)
- the process of writing an Individual Educational Program
- the process of pupil appraisal for eligibility, interagency planning
- responsibilities of the schools (Regulations for Implementation of the Exceptional Children's Act)
- the Louisiana School Directory with complete information on the services offered by the State Department throughout the state
- an annotated reading list of books reviewed by parents
- Parent Conferences on Special Education

Department of Health and Human Resources - booklets on:

- financial planning and estate planning (the Developmental Disabilities Council)
- evaluation, diagnostic and treatment services available from the Handicapped Children's program
- a comprehensive directory of services available throughout the state, including infant programs, respite care, substitute family care, and residential care.

East Baton Rouge Parish School System offers:

- a directory of services
- a parents' handbook

East Baton Rouge Junior League offers:

- a catalog of services for children with special needs

Bookstores offer:

- Come Care with Me by Lottie Krim

* Somebody Else's Kid by Torey Hayden
* One Child by Torey Hayden
* Reach for Fitness by Richard Simmons
* Handling Your Cerebral Palsied Child at Home by Nancy Finnie
* The First 12 Months of Life - Frank Kaplan, Editor

Magazines include:

* The Exceptional Parent
* Education of the Visually Handicapped
* Newsletter from the Down Syndrome Congress
* Newsletters from the National Information Center for Handicapped Children and Youth

There are an enormous number of other publications. These are just a few that various parents have recommended.

Support Groups

Support groups are often helpful to parents of young handicapped children. At the meetings, a mother may find a friend, a mentor, or a fellow advocate. The meetings also give parents a chance to exchange information and hear speakers on topics of interest to them.

In Region 2, a number of groups are available.

- Louisiana Society for Autistic Children
- The Baton Rouge Neurological Association
- Bereaved Parents
- Down Syndrome Awareness Group
- Early Intervention Programs - Baton Rouge, Hammond, Donaldsonville
- La Leche League
- Neonatal Intensive Care Unit Group at Woman's Hospital
- Parent/Teacher Organization of LeBlanc School in Gonzales
- The Association for Retarded Citizens (East and West Baton Rouge Parish, Livingston, Tangipahoa, Iberville, and Ascension Parishes)
- Advocacy Center for the Elderly and Disabled
- Louisiana Epilepsy Association
- Citizens Cooperating for the Education of the Deaf (COED)
- Council for Exceptional Children
- PROMPT (Parents Reaching Out Model Parent Training)
- The Parenting Center
- Louisiana Association for the Deaf/Blind
- Spina Bifida Association

Equipment

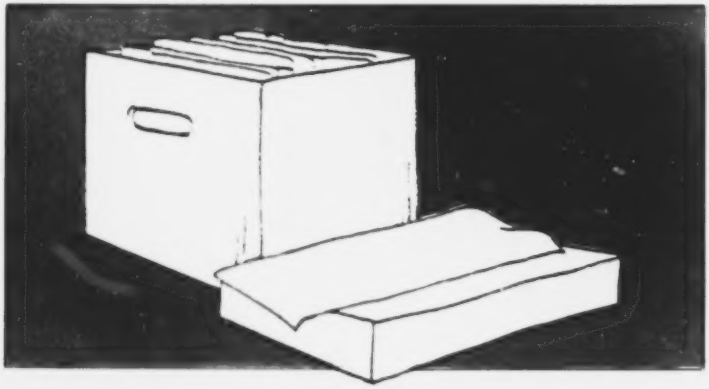
When the Lions' Club called Sarah's grandmother for a donation, they ended up donating a hearing aid to Sarah. Civic clubs, state agencies, and family members often team up to get the equipment a handicapped child needs. Many sources are available. A sampling is listed below.

- The Lions' Club - gives hearing aids, glasses, etc.
- The Cerebral Palsy Center - lends wheelchairs, corner seats.
- The state through LSD or LSVI - gives equipment for deaf and blind
- Private insurance - pays for corrective shoes, etc.
- Baton Rouge Sports and Physical Therapy Center - orders and sells adaptive strollers, orthokinetic wheelchairs, gymnastic balls
- Louisiana Respiratory Therapy Center - sells/rents oxygen tents, heart monitors
- A&P stores - sells a disposable super toddler diaper for children over thirty pounds. Goes to forty-five to fifty pounds

Home and friend made equipment:

- A carpenter - can build parallel bars, corner tables, exercise tables, overhead ladders
- A parent - can make padding or find a block to position a child
- A parent - can use a weighted toybox on rollers for the child's walking practice
- A parent - can make extra large training pants by sewing the heavy padding from a large pair of training pants into a pair of regular pants
- A parent - can make bath mits from terrycloth to enable the child to grip the soap

Record Keeping



"Good files are as important as a good doctor." It's essential to save reports about and evaluations of the handicapped child. However, the filing system should not be so complicated that it's one more chore.

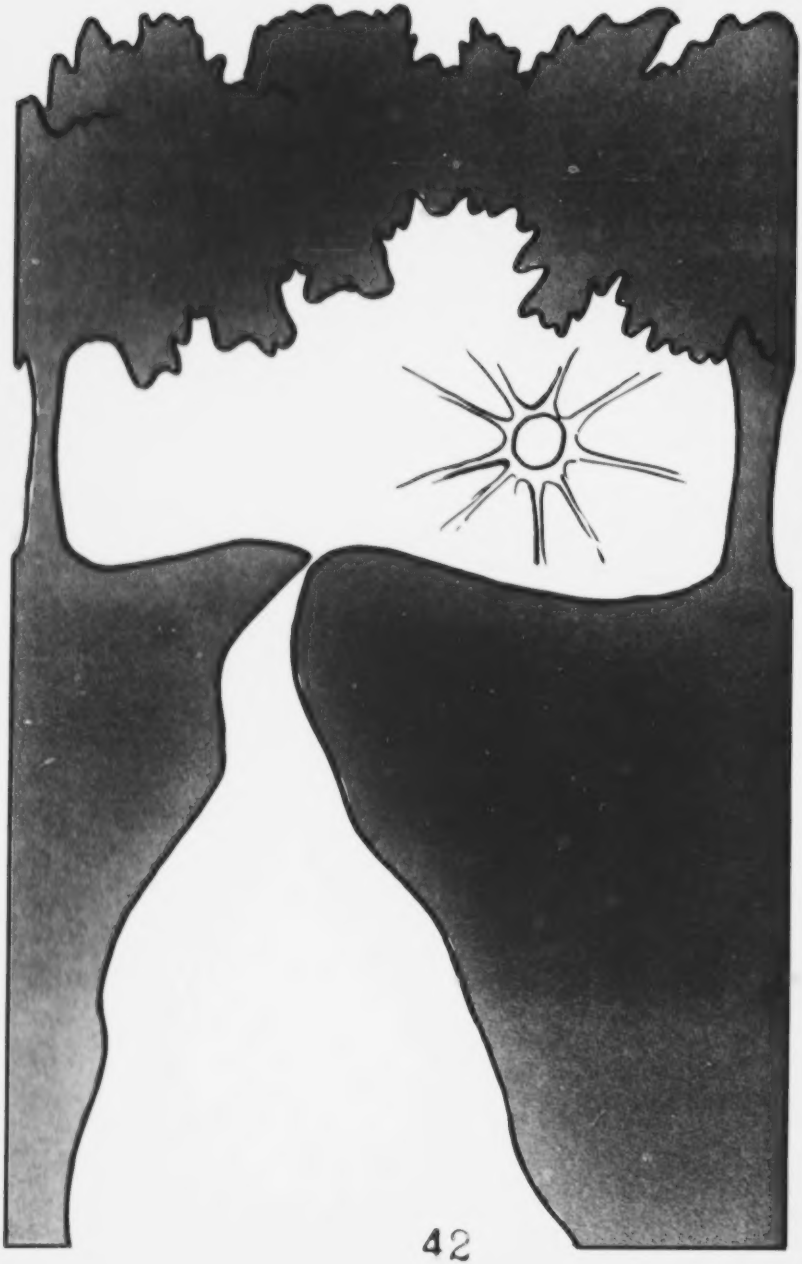
There are a number of possible choices.

- Manila envelopes with labels
- Boxes
- A notebook binder - use tabs, keep information in a box or basket and put in appropriate categories several times a year, as needed
- File folders - can keep on a shelf or in a file cabinet; can save all information in one place, and file here periodically

Categories can be medical information, articles on nutrition, pending legislation, evaluation, I.E.P.s, early intervention techniques, workshop materials, etc.

Information can be filed by date, by doctor, by teacher, or just alphabetically.

One excellent way to pull what you need from your mountain of paper is to keep two running lists in a separate file. One should be medical milestones, by date, such as tubes in ears, cleft palate surgery, etc., and the other can record, by date, developmental milestones, such as sitting up, putting weight on feet, etc. This information will be requested many times, whenever you start a new program or see a new doctor, so it is a most useful list to have.



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Thomas G. Clausen
State Superintendent
Louisiana Department of Education
P.O. Box 94064
Baton Rouge, LA 70804-9064

"DISABILITIES INFORMATION ACCESS LINE AVAILABLE"

"Call DIAL." That's the motto of the newly developed statewide computerized information and referral system for persons with developmental disabilities. This service will provide a central source of information on services provided by major state agencies, hospitals, associations, private service providers, support groups and various other state and public agencies. Family members and providers of services for developmental disabled persons are also encouraged to use the toll free line established by the Developmental Disabilities Council. The toll free line will be operationalized on a pilot basis October 1, 1987.